CHAPTER 5: COORDINATION AND LINKAGES

This chapter describes how various governmental and non-governmental agencies in South Carolina coordinate to deliver comprehensive HIV prevention services, and how prevention activities are linked to services that prevent or delay onset of illness in persons with HIV.

1. Coordination

Why is Coordination Important?

The purpose of coordination is to facilitate the accomplishment of state and local HIV prevention goals through enhanced communication and planning between public health agencies, other agencies, and individuals. Health districts and communities throughout the state organize and plan HIV prevention and care services based on their local resources (including skills, fiscal, and personnel) and culture. Such coordination maximizes use of local and state resources to strengthen prevention and care efforts in South Carolina.

Partnerships between programs facilitate coordination and relates to sharing information, materials, or client referrals. Coordination is an active process intended to enhance group efforts toward a common goal or purpose, and in doing so:

- blends, integrates, and maximizes resources;
- facilitates complementary and supplementary programs; and
- leads to a system in which the whole is greater than the sum of its parts.

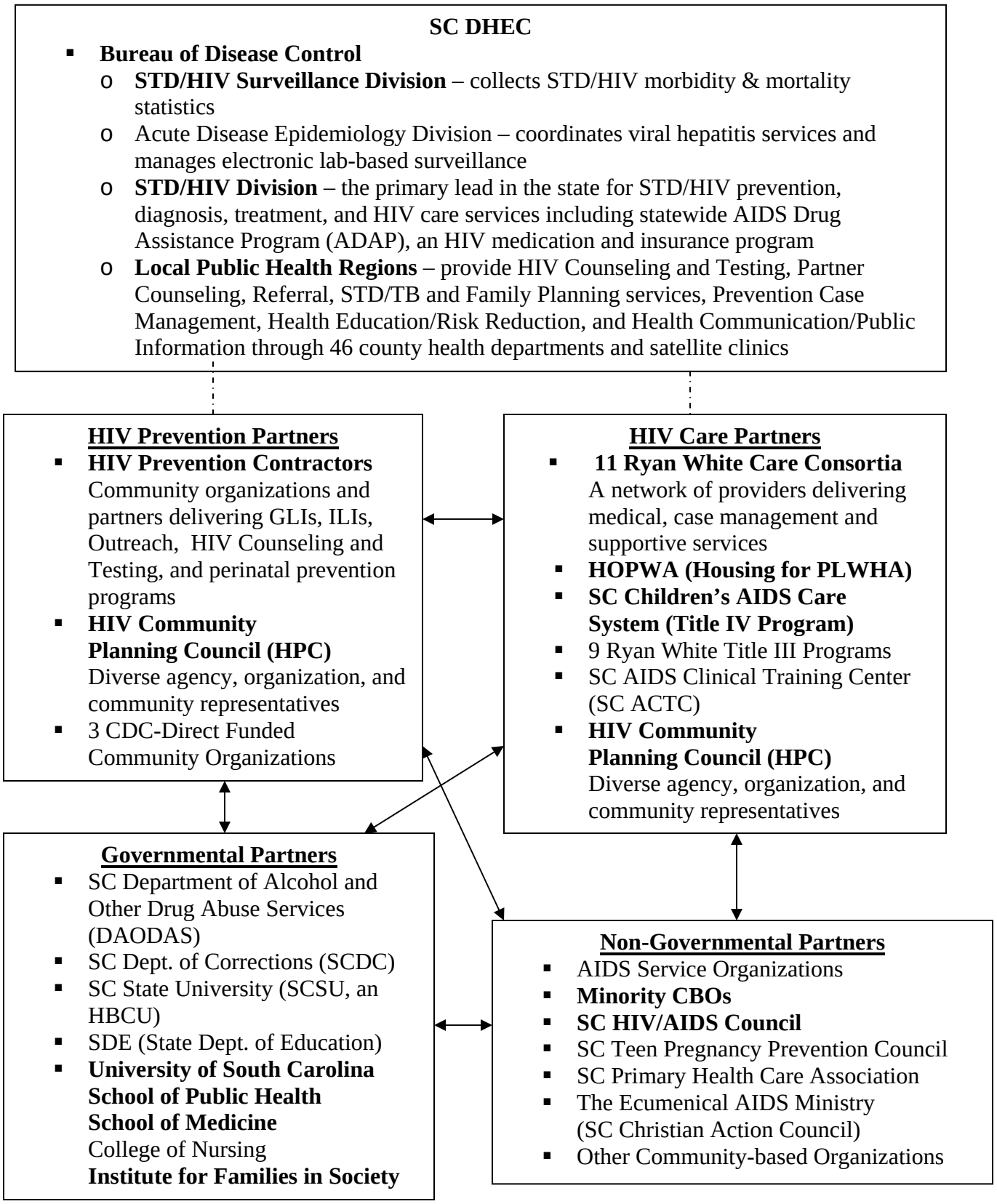
The benefits of coordination are compelling and beneficial to the public and include:

- standardized and consistent prevention and early intervention messages;
- reduced duplication of effort;
- maximized use of limited resources;
- increased access to funding opportunities and other resources;
- increased capacity and improved quality of services to individuals and communities because of shared knowledge and improved planning abilities; and
- expanded technical assistance opportunities for participating communities, agencies, and individuals through interaction with others who provide complementary skills, knowledge, or other resources.

Many providers experience or perceive disadvantages or threats related to participation, despite all the benefits coordination offers. The strongest disincentives to coordination include:

- increased competition for limited dollars or resources;
- concern by individuals or agencies that a coordinated process might result in their loss of control over programs or resources;
- a perceived change in equity or standing within the power structure; and
- time constraints of participants.

The schema below presents an overview of coordination and linkages. For abbreviations, please refer to the *Key* at the beginning of this plan.



NOTE: Bolded Partners/Organizations receive DHEC funds for HIV prevention and/or care services

How is HIV prevention and care services planning coordinated in South Carolina?

In 2004, a stakeholder group of representatives identified from the Ryan White CARE Act programs and the CPG was organized with the specific task of integrating planning for prevention and care services in South Carolina. The stakeholder group, composed of representatives from agencies/organizations providing prevention, care, or both prevention and care services, has developed bylaws and is presently working on a policies and procedures manual and membership application. The new integrated planning body, the SC HIV Planning Council (HPC), will officially begin its work in January 2005, with the primary goal of fully integrating planning for HIV prevention and care services in South Carolina. Twenty-five (25) voting members will serve on the Council, representing a balance of prevention and care providers, and will include a minimum of five consumers. Members of the HPC will be drawn from present representatives on the CPG and from among Ryan White care and support service providers, with representation also sought from Corrections, ATOD, and Mental Health programs.

The HPC will specifically incorporate the principles of Parity, Inclusion, and Representation in its membership, and will meet CDC and HRSA guidelines for planning bodies. The structure of the group includes five committees: (1) Prevention, (2) Care and Support Services, (3) Consumer Advisory, (4) Membership, and (5) Needs Assessment. Membership on the committees will be open to interested participants from across the state, with the exception of the Consumer Advisory Committee that is limited to and composed entirely of persons living with HIV.

The Council will have two co-chairs: the Planning Coordinator from DHEC and an elected community co-chair. The Planning Coordinator, hired in May 2004, was the Project Coordinator for the SC HIV Services Planning Project, the HRSA-funded multi-agency project (1990-91) to develop a comprehensive statewide plan (and a model regional plan) for services for persons living with HIV. The plan served as the foundation for the present networks of Ryan White CARE Act-funded care consortia and prevention collaborations in South Carolina.

How are prevention services coordinated in South Carolina?

State Health Department

The DHEC STD/HIV Division administers the CDC HIV prevention, STD prevention programs, Ryan White CARE Act Title II and Title IV, and HOPWA programs. This organizational structure ensures collaboration of state and local staff and coordination of planning and funding mechanisms. The STD/HIV Division maintains a strong collaboration with other Health Department programs, such as Maternal and Child Health programs, TB, Immunizations, and the public health laboratory. Staff from these programs coordinate cross-program training, clinical services, and quality assurance efforts.

DHEC has developed a comprehensive approach to STD/HIV prevention, which includes:

- active surveillance to track the STD/HIV epidemics;
- cost-effective routine screening and treatment of at-risk populations;
- mobile screening efforts to reach populations who are not accessing clinical services;

- partner notification and referral services;
- targeted health education/risk reduction interventions; and
- on-going training/quality assurance activities.

Prevention programs are delivered primarily by health districts/regions (covering 46 county health departments) and community organizations such as local alcohol and drug abuse commissions, community action councils, AIDS service organizations, and minority community based organizations.

Selected examples of coordination among governmental and non-governmental prevention providers for planning and delivery of services, capacity building, needs assessments, and training are highlighted below.

Local HIV Prevention Contractors

The primary mechanism for coordination of health education/risk reduction services has been through local HIV prevention collaborations. DHEC provided funding to eleven HIV Prevention Collaborations covering all but two counties in the state (see Figure 1), in response to a need identified by the Statewide HIV Prevention Community Planning Group (CPG) to increase the capacity of local organizations to conduct HIV prevention activities.

Each Collaboration in the state involves partnerships with various and diverse agencies and organizations. Member organizations and community partners include local alcohol and drug abuse agencies, health departments, county teen pregnancy councils, housing communities, youth-serving organizations, corrections facilities, shelters, fraternal organizations, as well as representatives from minority organizations. These organizations include, but are not limited to: Sistercare, Columbia Housing Authority, Camille Griffin Graham Women's Correctional Institution, Broad River Correctional Facility, Lexington/Richland Alcohol and Drug Abuse Council, Lexington Department of Social Services, Morris Village In-Patient Programs, Killingsworth, Lexington County Jail, Women's Resource Center, 100 Black Men of Greater Columbia, Orangeburg Area Mental Health, Minority AIDS Council, Brooks Health Center at SC State University, Alpha Xi Chapter of Delta Sigma Theta Sorority, Inc., Tri-County Healthy People 2000, Alpha Omicron Zeta Chapter of Zeta Phi Beta Sorority, Inc., Lowcountry Healthy Start, OCAB Head Start, AFFIRM Youth, Stephen's House, Out of Bounds, New Attitude, Metropolitan Community Church, Greenville Detention Center, Greenville Free Medical Clinic, Anderson Free Medical Clinic, Piedmont Treatment Center, Greenville Alternative School, Young Men of Vision and Progress, and New Life Center.

The Collaborations 1) created an association of organizations that work together by developing a working structure (board, bylaws, etc.) to create a plan to meet the needs and fills the gaps in services, and 2) delivered services to populations at greatest risk based on the SC HIV Prevention Plan Epi Profile, local epidemiological data, and local needs assessment. The objectives and activities varied by area but were based on target populations, especially racial and ethnic minorities. In the past, each collaboration had a designated lead agency that DHEC contracted with, which managed the administration of activities for the group. Each lead agency

hired needed staff, supervised the planning, monitoring, and evaluation activities, and submitted quarterly reports.

SC DHEC devoted significant resources to strengthen these collaborations through capacity building, providing training and technical support, in an effort to institutionalize the collaborations in their local areas. Beginning January 2005, a new cycle of HIV prevention funding will go directly to agencies or organizations that plan and implement local activities based on the collaboration model of interconnectedness and resource-sharing, but greatly reducing the overhead costs involved with maintenance of the collaboration structure. Newly funded prevention contractors must demonstrate community partnerships and support as well as the ability to reach priority populations with priority interventions.

Perinatal Prevention Coordination

To achieve reductions in perinatal HIV infection, DHEC receives federal HIV perinatal prevention funds from CDC and Ryan White Title IV funds from HRSA. These programs focus on ensuring that Public Health Services Guidelines for Preventing Perinatal HIV Transmission are practiced in South Carolina. These guidelines include routine HIV screening of pregnant women, rapid HIV testing during labor and delivery if indicated, access to antiretroviral treatment for HIV infected pregnant women and their children. DHEC's perinatal prevention activities focus on provider education and training, linking HIV exposed infants to care services, monitoring perinatal transmission rates, prevention case management for HIV infected pregnant women and education/outreach to high risk women. One example of coordination is the University of South Carolina Department of Medicine Perinatal HIV Prevention Case Management Program (USC PCM). HIV infected pregnant women in Columbia are recruited from the Department of Obstetrics at USC for PCM services; these women may also be receiving HIV care from the Title II clinic at the Department of Medicine. Intensive case management services are provided to pregnant HIV-positive women, many of who experience complex psychosocial HIV issues that increase the difficulty of adhering to recommended antepartum or postpartum therapy and/or care plans. Women may also be linked to Title IV consumer advocates for peer education. Following delivery, the women are linked to Title IV providers.

African American Communities Initiative (AACI)

African American Communities Initiative (AACI), funded by Ryan White Title IV, includes targeted health education, case-finding through counseling and testing, and linkages of patients with consumer advocates. The primary goal of AACI is to increase case-finding strategies for African American youth and women to recruit and maintain those positive in HIV care and supportive services. AACI activities are also closely linked with the state's STD/HIV prevention and family planning services infrastructure to avoid duplication and ensure coordination and maximize resources.

Project staff network with key organizations serving African Americans at risk to provide on-going support for prevention education to enhance referral mechanisms to primary care services. Staff provides and/or coordinates with existing health education staff, STD/HIV prevention education and referral sessions that focus on HIV prevention and primary and specialty care

services. Project staff also coordinates with local HIV prevention providers conducting community-delivered HIV counseling and testing services targeting African American adolescents and young adults at risk in areas of highest morbidity such as Columbia, the Upstate and Charleston. Title IV health education staff collaborates with the HIV prevention partners to design health communication messages for radio stations that target priority population audiences. These health communication messages contain HIV/STD prevention messages as well as prenatal testing messages targeting young African American women who are pregnant or who are thinking about getting pregnant. These messages announce where counseling and testing events will be held across the state.

Syphilis Elimination Project

In 1999, the Centers for Disease Control and Prevention launched a national plan to eliminate syphilis in the United States (US), awarding funding to states and cities with highest syphilis cases. DHEC has developed syphilis elimination activities including jail screening, outbreak response teams, enhanced community education and outreach. A major component of the syphilis elimination project is mobile screening. The mobile unit is a 'traveling clinic', offering free testing for syphilis, HIV, Chlamydia, and gonorrhea in counties with high syphilis rates. The mobile screening enables DHEC to target populations with appropriate resources, culturally competent staff, creativity, appropriate messages and strategies and strong community involvement to tackle the issue of syphilis. Over the past three years the mobile unit staff has strengthened current partnerships, opened opportunities for new partnerships, and made strides working with businesses, the historically black colleges, county detention centers and the Latino community. Outbreak response teams provide intensive outreach, syphilis and HIV screening and partner notification services. South Carolina's infectious syphilis cases continue to decline as a result of these strategies. In 2003, the number of cases dropped to 92 from 136 in 2002, and 380 in 1997.

DHEC Office of Minority Health and the AIDS Demonstration Project

The DHEC Office of Minority Health, one of the STD/HIV Division's strongest partners, collaborates with community-based minority serving organizations to coordinate capacity building skills workshops, consultation and technical assistance. The HIV/AIDS Demonstration Project, funded with Congressional Black Caucus monies, strengthens the capacity of minority community based organizations (MCBOs) to provide HIV prevention services. The project, in its fourth year, has a project advisory committee that includes STD/HIV Division staff, representatives from primary care organizations, African American churches, African Americans living with HIV, DAODAS, faith communities/organizations, and others. The project coordinator is a visiting member of the HIV Prevention Community Planning Group. The MCBOs identified for capacity building are included in the STD/HIV Division's mailing lists to receive announcements for upcoming training events, funding opportunities, and other HIV-related news. Additionally, the Office of Minority Health and the STD/HIV Division collaborate to sponsor events to promote HIV awareness in the African American community.

Examples of collaborative events include the following:

- **The HBCU HIV/AIDS Summit** is a statewide collaborative effort coordinated by the SC DHEC-Office of Minority Health for the state's Historically Black Colleges and Universities (HBCUs). Other partners include the Ryan White Title IV African American Communities Initiative, DHEC District Health Education staff, faith communities, and HIV prevention contractors. The purpose of the Summit is to engage HBCUs in addressing HIV/AIDS on university/college campuses and the surrounding communities with an emphasis on implementing and institutionalizing HIV/AIDS prevention into HBCU curricula and activities. The Summit focuses on African-American students that attend HBCUs in South Carolina; however, other students that attend majority universities and colleges in the state are not excluded. It is planned to have this Demonstration Project used as a model for each of the HBCUs to use an am implementation instrument for each of their campuses in order to develop and host HI/AIDS Summits on their college/university campuses beginning in 2005.
- **The Minority Community Based Organizations (MCBO) Institute** was developed as a capacity-building effort of the SC DHEC Office of Minority Health, with a primary focus on education and training. The two-day Institute, targeting grassroot organizations that provide HIV/AIDS prevention services to African Americans, provides an opportunity to enhance and/or increase organizational and programmatic skills of the MCBO participants.
- **Cultural Competence in Serving Hispanic/Latinos**. This workshop included an introduction to the basic cultural competence principles, concept and skills to enhance efforts to effectively reach and service the Hispanic/Latino populations. The workshop explored Hispanic and Latino beliefs, values and customs, as well as existing cultural assumptions and their relevance to service providers. Discussions were held on current barriers to the delivery of services and ways to overcome those barriers, as well as a review of Hispanic/Latino population HIV/AIDS data in South Carolina
- **HIV/AIDS Grant Writing – A Beginners' Workshop** provided an overview of grant writing techniques commonly used by entities applying for funding from public (federal, state and local) and private/philanthropic organizations. The workshop reviewed the eight basic components of grants, with a focus on the type of information HIV/AIDS proposals should contain. There was also a session on where to search for grants; how to read and respond to a request for proposals, and the timeline/work plan needed for getting the proposal written and submitted. The main focus of the workshop was on public funds; however, differences between applying to public agencies, corporations, and foundations were discussed. This full-day, hands-on grant-writing workshop also included interactive components with group activities.
- **Building Healthier Communities Statewide Capacity Development Meetings,** a partnership with the federal Office of Minority Health Resource Center (OMHRC), utilized state offices of Minority Health, local CBOs, faith-based organizations, ASOs, health departments and community leaders, was formed to coordinate a series of national forums that highlighted the capacity development needs within these organizations. More specifically, these meetings aimed to clarify the needs of rural grassroots minority organizations in delivering HIV/AIDS services to the diverse rural and ethnic communities within their states. In 2004, the daylong meeting was held on Thursday,

May 20, at Brookland Baptist Church, a very large African American congregation in West Columbia. Follow up for this meeting includes capacity building trainings throughout the year to address the identified needs of the organizations and individuals who attended.

- **The 501(c)3 Workshop a**cquainted participants with the application process, including prerequisites and requirements, for Recognition of Exemption under 501(c)3 of the Internal Revenue Code. This workshop gave participants "hands on" experience in completing the 501(c)3 application (IRS Form 1023) and other applicable forms and documents, as well as the specific steps required for recognition of exemption as an eleemosynary organization.

State Department of Education

South Carolina's local school boards, with technical assistances from the State Department of Education (SDE), are required to provide instruction in age-appropriate reproductive health and sexuality education to students during the middle and high school years under the Comprehensive Health Education Act (revised 1988).

The SDE Healthy Schools Program (HSP), which is a cooperative agreement with DHEC, supports these efforts by providing training, resources and technical assistance to the 85 school districts throughout the state. The HSP also employs an HIV Program Coordinator who works with local school districts to provide teacher training and to build upon and utilize linkages with community based organizations, DHEC, and other health agencies.

HIV prevention education services, provided by the HSP, are directly funded by the CDC Division of Adolescent and School Health (DASH). DASH also provides separate funding to the Healthy Schools Program to conduct the Youth Risk Behavior Survey (YRBS). The YRBS is conducted bi-annually by SDE or an identified sub-contractor. Results of the YRBS are widely shared with public health and HIV/STD prevention providers for planning and evaluation. Overall, CDC DASH funding provides for coordinated HIV/STI prevention education for school age youth in South Carolina.

SC Department of Alcohol and Other Drug Abuse Services

The SC Department of Alcohol and Other Drug Abuse Services (DAODAS) contracts with DHEC for the provision of HIV Early Intervention Services and Resources to clients in the statewide alcohol and drug abuse system. Through establishment of this contract, the two agencies created an active referral system between county health departments and county alcohol and drug abuse agencies, training for public health staff on substance abuse risk assessment, and training for substance abuse staff on communicable disease issues. The contract is designed to provide HIV counseling and testing services statewide targeting substance users in health department, local alcohol and drug commissions, and community settings. The contract also includes funding to support Hepatitis C training and education through the SC Hepatitis C Coalition and testing for Hepatitis C in county health departments.. DHEC receives 34.4% of the 15% Substance Abuse Prevention and Treatment block grant HIV Early Intervention set-aside total from DAODAS for implementation of these services. DAODAS also has funded

treatment counselors across the state at several local alcohol and drug abuse commissions that work directly with this high-risk population in need of alcohol and/or other drug services.

SC HIV/AIDS Council

SC DHEC coordinates several initiatives with the SC HIV/AIDS Council (SCHAC), a primary prevention and supportive services partner in South Carolina. The STD/HIV Division contracts with SCHAC to conduct community-based syphilis elimination initiatives in five (5) counties within the state. SCHAC works collaboratively with several DHEC-funded HIV prevention Collaborations to maximize resources by integrating HIV and syphilis community assessments, condom distribution, and local street outreach efforts into local HIV prevention efforts. SCHAC Syphilis Elimination staff assisted in creation of two 501(c)3 community-based coalitions and provides on-going technical assistance services upon request to ensure the facilitation of prevention activities within the two rural counties.

Efforts coordinated through local coalitions includes: a) dissemination of syphilis elimination resources, b) group level interventions (GLI), and c) syphilis screening coordinated by contractual Syphilis Elimination Outreach Coordinators within the five high prevalence counties. Coordination of activities (e.g., street outreach, GLI, and individual level interventions) are conducted in partnership with local health department staff (e.g., health educators, disease intervention specialists, etc.) to ensure implementation of HIV/STI interventions to high risk populations.

SCHAC is also a CDC directly funded community based organization for two projects. SCHAC is funded to provide community based HIV counseling and testing targeting African Americans at risk. They provide both in-house and mobile rapid HIV testing and prevention counseling to high and very high-risk clients. Partner counseling and referral services are coordinated with local and state health departments through a Memorandum of Agreement. SC DHEC staff assists by sharing resources and providing support to ensure quality assurance measures are linked with SC DHEC protocol. The second project, Between Brothers, targets young African American men who have sex with men through outreach, referrals to testing, and small group interventions.

CDC Direct-Funded Community Based Organizations (CBOs)

In 2004 three CBOs in South Carolina were awarded direct HIV prevention grants from CDC for 2004 – 2009. The CBOs/projects are:

1. South Carolina HIV/AIDS Council: HIV Counseling and Testing; ***Community Promise*** and ***Voices*** interventions for HIV positive persons and very high-risk persons in the Columbia area
2. Palmetto AIDS Life Support Services: Prevention Case Management for HIV positive African Americans; ***Healthy Relationships*** (for clients enrolled in Prevention Case Management in their 8-county service area) and ***Popular Opinion Leader*** (for high-risk African Americans in the Columbia area) interventions
3. HopeHealth: HIV Counseling, Testing, and Referral for High Risk Individuals; Rapid Testing in Non-Clinical Settings for High Risk Individuals; Prevention Case

Management for Persons Living with HIV; Integration of Prevention Services into Medical Care for People Living with HIV; **SISTA** Project for seronegative women at very high risk for HIV infection; serving the six-county Pee Dee region, including Chesterfield, Darlington, Dillon, Florence, Marion, and Marlboro counties.

Training and Capacity Building

Coordination for training and capacity building is essential to maximize limited resources and address training needs of prevention providers as well as in some cases, care and supportive services partners. The STD/HIV Division coordinates training on effective behavioral interventions, prevention counseling, STD clinical updates, Red Cross HIV Starter Facts, HIV care and treatment, and capacity building topics. Key partners involved in planning and coordinating training include the SC AIDS Clinical Training Center (University of South Carolina, Department of Medicine is the state contractor of the Southeast AIDS Training and Education Center - Ryan White CARE Act, Section F), DAODAS, and others. The Division conducts routine assessments on training needs and offers training workshops open to all prevention partners, minority CBOs, and care providers. National and regional technical assistance providers are invited to present training on diverse issues identified in training needs assessments.

Faith-based Initiatives

Prevention providers acknowledge the importance of the church's role in HIV prevention, and particularly as a mechanism to reach African Americans. Prevention contractors, health department staff and other organizations work collaboratively with churches to coordinate and implement prevention activities.

The SC DHEC Office of Minority Health provides much support to faith-based organizations for HIV prevention and supportive services through mini-grants, sole source contracts, and identified special funding. These organizations plan, support, and implement HIV and complementary health-based programs for their members, often in rural and underserved areas of South Carolina.

The Ecumenical AIDS Ministry (TEAM) is a program of the SC Christian Action Council. This ministry builds church-based Care Teams that provide supportive services to persons living with HIV/AIDS. A second function of the Teams is to promote AIDS awareness and education among members of the congregation by establishing educational programs/libraries in churches, working with clergy and lay leaders, and talking about ministry during special events such as AIDS Sunday or World AIDS Day. Some churches also offer services of healing and support. The coordinator attends local collaboration and Ryan White care provider meetings, and assists in promoting the statewide HIV/STD conference and other training events among its members.

The SC HIV/AIDS Council is the creator and now financial conduit for the Interfaith AIDS Resource and Education Coalition (I-C.A.R.E.) that is funded through the SC Department of Alcohol and Other Drug Abuse Services. The mission of the I-Care Coalition includes the provision of HIV/AIDS/STI education, skills-building training, as well as enhancing access of

HIV/STI resources to faith-based denominations. I-CARE church members maintain a particular emphasis on engaging black churches in prevention activities due to the disproportionate number of African Americans directly impacted by HIV/AIDS in South Carolina. The organization's goal includes the intent to encourage HIV testing and prevention counseling as a behavioral action designed to slow down the spread of HIV/AIDS.

Challenges in Coordinating Prevention Services

In South Carolina, the primary challenges in coordinating prevention services includes:

- Lack of communication among providers due to multiple tasks limiting time or opportunities to network or interact with other providers.
- Staff turnover, especially at the local service delivery level, impeding on-going communication and partnerships.
- Lack of resources at the state and regional level to facilitate dedicated collaborative activities among prevention providers, especially with mental health services.
- In some areas, increased competition for limited dollars or resources among multiple organizations creates reluctance to share information and coordinate services.

As state, local and federal resources decline or remain level in the face of growing HIV prevalence, collaboration and coordination among existing and new prevention providers will need a greater focus. DHEC and other key partners will continue to explore ways to facilitate communication among prevention providers, to create opportunities and incentives for maintaining current or forming new partnerships, to leverage resources (staff, funds, equipment, office locations, etc) among different community organizations and agencies. DHEC will also continue to offer or sponsor various training and capacity building activities for prevention providers to improve staff skills in delivering prevention programs, evaluating impact of services, administering/managing funds, and securing additional resources.

2. Linkages

Why is linkage between prevention and care/supportive services important?

CDC's initiative, *Advancing HIV Prevention: New Strategies for a Changing Epidemic* (published in the April 18, 2003 issue of the Morbidity and Mortality Weekly Report), focuses on the increased need to reduce barriers to early diagnosis of HIV infection and increase access to quality medical care, treatment, and ongoing prevention services for those diagnosed with HIV. The basis for CDC's initiative centers on recent advances in HIV treatment have significantly impacted the lives of people living with HIV disease and the approaches to responding to the epidemic. HIV medications have delayed the onset of AIDS and offer hope of reducing transmission to others by lowering viral loads and potentially decreasing the level of one's infectiousness.

There are many challenges for persons living with HIV disease, including but not limited to:

- Adhering to sometimes difficult treatment regimens;
- Dealing with side effects of medications;
- Managing the high costs of care and medications;

- Dealing with other competing life events;
- Handling depression;
- Dealing with stigma, particularly in rural areas; and
- Recognizing denial in self and/or others.

Ongoing prevention support services must be available to help persons living with HIV disease to be successful with medication adherence to prevent or delay illness, and to help them adopt and maintain healthy behaviors including steps to prevent infecting others. Supportive services that link persons to stable, long-term housing, substance use treatment, or mental health counseling may also enable persons to reduce risk behaviors associated with HIV transmission.

Early identification of HIV status and linkage to HIV care and treatment services are essential for persons to benefit from these and other services. Data from several studies in other areas of the country indicate that 30-40% of persons with new HIV diagnoses are not linked to an HIV care provider within 12 months of their HIV diagnosis. A recently completed Antiretroviral Treatment Access Study ("ARTAS") in four United States (US) cities indicates that providing case managers to help socioeconomically disadvantaged newly diagnosed persons into care significantly increases the percentage of persons who see an HIV care provider once within six months and twice within twelve months after their initial HIV diagnoses. After one year, 64% of case managed participants and 50% of non-case managed participants were linked to care. Such case management was also cost-effective (approximately $1,000 per additional person successfully linked). The ARTAS model required only two to three face-to-face meetings on average with a case manager over a maximum of three months.

Many persons at greatest risk for HIV or who are HIV-infected have multiple health and social service needs. Many persons living with HIV may have other co-morbid diagnoses, such as substance use, hepatitis, mental illness, or tuberculosis. Needs assessments in South Carolina consistently indicate a high likelihood for depression among persons with HIV, particularly women in rural areas, creating a need for mental health and counseling services. A significant proportion of our target populations are likely to be uninsured or underinsured and have low incomes, creating needs for supportive services such as transportation, food, housing, and/or job assistance training.

Prevention and care providers must acknowledge that a holistic, culturally competent, client-centered approach is essential in order to increase effectiveness of both primary and secondary prevention. A recently discharged HIV-infected inmate is not likely to keep an initial appointment with the local HIV care provider when he/she has no job to obtain food, or reverts to substance use once back on the streets. Similarly, a woman in a dependent relationship with a partner prone to domestic violence is not likely to be successful in negotiating safer sex until relationship issues are confronted.

What are the challenges for effective linkages?

Successfully linking a person from a prevention activity such as outreach to counseling and testing, to partner counseling and referral services, to HIV patient care and to additional supportive services requires many elements. An effective, active referral system is a central component for effective linkages. It is important for providers to recognize that, even though essential services exist in our state, there are systems-level, provider-level and client-level barriers that may impede successful linkages.

Systems-level barriers may include:

- not offering services at times or days convenient for clients;
- locations that are difficult for clients to reach, particularly in more rural areas;
- lack of staff and resources to meet the demand/need for services, thus turning away clients;
- having waiting lists; and/or
- not being able to meet all a client's needs.

Provider-level barriers may include:

- lack of skills to engage clients, inhibiting the accurate assessment of psychosocial and health needs;
- lack of knowledge of available services and resources, preventing active referrals;
- lack of knowledge of updated care and treatment guidelines and methods;
- lack of cultural competence skills, impairing effective communication with clients and their families; and/or
- lack of foreign language skills to effectively communicate with non-English speakers.

Client-level barriers may include:

- lack of resources for transportation to care and other services;
- denial of one's illness;
- other competing needs and issues, such as homelessness or dual diagnoses;
- fear of stigma or lack of confidentiality, preventing them from making or keeping regular appointments;
- lack of knowledge that services exist or how to successfully access existing services; and/or
- difficulty in navigating complex care or service systems, creating despondency or frustration with providers.

To better identify and address these and other challenges, the state involves HIV-positive consumers in planning and delivery of services at the local and state level. The Ryan White Title IV Consumer Involvement project hires parent advocates at each regional care center to enhance cultural competence, increase consumer involvement in advocacy roles, planning and evaluation, and to provide a supportive role in maximizing medication adherence.

What are the Key Linkages and Challenges in South Carolina?

South Carolina has developed an extensive infrastructure of linkages between prevention and HIV care services. Many services in county health departments and community health centers are integrated, making it easier for persons to receive a range of prevention services such as HIV counseling and testing, STD diagnosis and treatment, TB screening, and reproductive health services. Additionally, many agencies in South Carolina are lead agencies for both HIV prevention and care services, allowing for a seamless transition for persons diagnosed with HIV. Integrated services can facilitate both effectiveness and efficiency of primary and secondary prevention efforts.

South Carolina has several strategies conducted and planned in response to CDC's "Advancing HIV Prevention: New Strategies for a Changing Epidemic" initiative. In July of 2003, the CPG prioritized persons living with HIV as the number one priority population in the state's Comprehensive HIV Prevention Plan. State health department staff has also been working with local health department staff and prevention contractors to begin to redirect services in 2004 to focus on persons living with HIV. To assist with this shifting of interventions and target populations, prevention staff teamed up with the Ryan White Care staff and hosted a joint meeting of local prevention and care providers in September of 2003 (including Titles II, IIIb, and IV) to discuss the new initiative and look at ways to enhance cooperative efforts. Staff presented a summary of the initiatives at the meeting and participants identified some initial ideas for integrating prevention into care services. Follow-up meetings are being held to facilitate communication and address specific prevention strategies for Title II providers. The meetings are also being used to plan specific approaches for screening and referral by hospital and other facilities in areas having an HIV prevalence rate of 1% or more.

Of the eleven Title II care consortia, seven agencies serve as the lead for both prevention and care services contracts with DHEC. In 2004, trainings and technical assistance meetings have been held to look at integrating interventions within the Ryan White-funded programs, such as prevention case management and individual level prevention activities focusing on reducing sexual or drug-use HIV transmission risk, and to closely link health department staff providing partner notification services in order to target persons most likely to be HIV-infected and refer them to care. Seven consortia included Health Education/Risk Reduction and/or prevention case management services as one of their 2004 plan objectives.

The SC Primary Health Care Association oversees 17 Federally Qualified Health Centers operating numerous satellite locations in medically underserved (and mostly rural) areas. The majority of these primary care clinics provide HIV testing services and nine sites also receive Ryan White Title IIIb funds for Early Intervention Services. Seven of these sites use Title IIIb funds to support HIV screening services to clients of their primary care facility. Additionally, the Medical College of Georgia, through its Title IIIb expansion grant, began offering services this year in Aiken. A contact list of all primary care sites is integrated with the STD/HIV Division's mailing list for training updates and meetings to allow for staff participation in relevant training.

Trainings have focused on integrating prevention for positive persons based on CDC curricula/training information. Although targeted to DHEC's prevention and Title II contractors, as well as Title IIIb and IV, staff from other organizations such as the primary care clinics and correctional facilities was allowed to participate.

To facilitate linkages, information about accessing counseling and testing services, other prevention services, Ryan White, HOPWA and other care services is available through the toll-free state AIDS Hotline operated by DHEC STD/HIV staff. For referrals, the hotline staff access an electronic database of all HIV-related services by county using the same software that local care consortia and HOPWA providers use (PROVIDE). Local case managers access the resource listings electronically. A committee periodically updates the listings. The database includes education/prevention, outreach, counseling and testing services, primary care, and support services. It describes statewide services available such as Ryan White CARE Act-funded programs, housing assistance, Department of Alcohol and Other Drug Abuse Services, Department of Mental Health, Community Long Term Care (Medicaid), church-based care teams, and others. Hotline and case management staff use the database to identify existing services and refer individuals to appropriate available services.

The STD/HIV Division also maintains a website which is accessible to the public <http://www.scdhec.net/hs/diseasecont/stdwk/html/stdindex.htm>. Information contained on the website includes:

- Surveillance report data for HIV/AIDS/STD;
- STD/HIV Prevention Information for Communities, including an overview of the CPG and the Community Planning Process, Collaborations, the SC Federal Materials Review Process, the Continuation Application, Partner Counseling and Referral Services, and Training;
- HIV Care and Support Information for Communities, including an overview of ADAP, and HOPWA;
- South Carolina Plans, including the SC HIV Prevention Plan and the SC Comprehensive HIV/AIDS Care Plan;
- Public Information Programs; and
- Information for Health Care Providers, including information on Prenatal Screening; and
- Additional Resources and Links.

Another resource tool is the Resource Directory developed by the Title IV African American Youth Initiative. The directory was developed in coordination with key youth-serving organizations in the Columbia area to enhance the referral system for adolescents from agencies where services are accessed. The directory provides a youth-friendly description of each service and is available for local agencies and service providers, and can be found on the Internet at http//:www.midlandsyouthdirectory.com.

The following is a description of the key related services in South Carolina and how clients are linked to:

- HIV testing, counseling and referral services;
- Partner counseling and referral services (PCRS);

- HIV care and support services;
- Perinatal HIV prevention services
- Homelessness prevention services (Housing Opportunities for People with AIDS – HOPWA);
- Substance abuse treatment services;
- Mental health services; and
- Correctional systems.

HIV Counseling, Testing, and Referral Services

The primary linkages to HIV counseling and testing services in South Carolina are made through:

- Partner counseling and referrals;
- AIDS hotline referrals;
- HIV prevention contractors and CBOs providing health education/risk reduction;
- Outreach strategies by community organizations, Ryan White Title III providers, the Ryan White Title IV African American Communities of Color Initiative, and DHEC mobile screening;
- Routine HIV screening in STD, TB, and Family Planning clinics;
- Routine HIV screening for pregnant women;
- HIV testing in several alcohol and drug abuse facilities;
- Public information/media awareness;
- Physicians/primary care providers; and
- Blood/plasma centers.

HIV counseling and testing services are available in each county health department. Approximately one-third (30%) of the annual number of newly reported persons with HIV in the state is diagnosed through the county health departments. More than 45,000 clients received counseling and testing services during calendar year 2003 (includes those routinely screened during other STD, TB or family planning services**).** Among the 640 clients whose tests were HIV positive, 380 (59%) were estimated to be newly diagnosed.

All newly diagnosed persons with HIV infection in counseling and testing sites are referred to existing care services. Depending on insurance status or personal situations, clients are referred either to private providers, Ryan White Care Consortia, Title III or Title IV providers. In order to facilitate referrals, county health department counseling and testing sites offer an initial CD4 and viral load test free to newly diagnosed persons with HIV. Screening for syphilis and tuberculosis is provided for all newly identified HIV-infected clients and referrals are made for treatment within the health department if necessary. Screening for Hepatitis C is also routinely provided. Staff also make referrals for drug treatment services, counseling, support groups, AIDS service organization services, Medicaid, and other services as appropriate.

An estimated 95% of all newly diagnosed persons at the health departments are provided their test results within 3 months and of these, all are provided an appointment to care. However, an estimated two-thirds (64%) of recently diagnosed persons served by local health department CTS

and partner notification services do not successfully become enrolled in care services within three months. Due to severe understaffing at most health departments, the existing referral system between the health department and the medical and supportive service providers does not allow for proper follow-up with newly diagnosed clients to document or verify if the appointment was kept. The agencies that receive the referrals are unable to make contact with the individual if they do not keep their appointments because they do not have the proper client authorizations to do so. Thus, the large number of newly diagnosed clients and the lack of referral coordination among the agencies both contribute to clients often not entering medical care in a timely manner.

To address the lack of capacity for health departments to follow – up on referrals to care, some health departments and Ryan White Care consortia have developed a mechanism for CTS staff to obtain consent for HIV care case managers staff to contact HIV positive persons who do not make their first care appointment.

In addition to county health department sites, HIV counseling and testing services are presently provided through 10 DHEC HIV prevention contractors; several alcohol and drug abuse treatment agencies; one CDC directly funded CBO in the Columbia area, and one CDC direct-funded CBO in Florence. These organizations all have either contracts or memoranda of agreement with DHEC and include referrals to primary care, partner counseling and referral services, and other services as appropriate. HIV counseling and testing services are also provided by primary care centers, and seven Ryan White Title IIIb projects for Early Intervention Services, which directly link HIV-infected persons to primary care.

Entry into HIV medical care is a complex issue for many individuals who are newly diagnosed. Barriers for many clients newly diagnosed actually completing referrals reported by counselors include denial of illness, not feeling “sick”, fear of confidentiality loss, other competing priorities Often people have no outward symptoms of the disease and therefore do not feel an urgency to get into care. Many clients state they will not enter care until their CD4 count is below 500. Prevention staff around the state report it may take as long as six months and as many as 2-3 contacts before an individual will enter care. In addition to the individual psychological reasons that people do not enter care in a timely manner, there are barriers within the care system that prevent early entry into care. For example, case managers and health care providers are typically only available during normal business hours, which may be inconvenient for working people. Also, in rural parts of the state, transportation continues to be a barrier to care for clients/families that must travel long distances to regional clinics.

Partner Counseling and Referral Services (PCRS)

Partner counseling and referral services provided by disease intervention specialists in local health departments are an effective intervention to link persons who have been exposed to HIV through sex or needle sharing exposure to HIV counseling and testing services. During 2003, local health department staff provided partner counseling services to 847 HIV-infected persons (both newly diagnosed and previous positive persons) who named 1720 sex/needle-sharing partners. Of the named partners with unknown or previous HIV negative test, 79% were tested after notification by PCRS staff. Among these partners who were tested, 11% were newly

diagnosed with a positive test; 31% of all named partners were HIV-infected (new and previous positives). PCRS staff also assists in referring both newly and previously HIV diagnosed persons to care services.

HIV Care and Support Services

The primary linkages to HIV care and support services in South Carolina are made through:

- Provider referrals from HIV counseling and testing sites;
- Referrals from physicians, primary care clinics, hospitals, and other providers;
- Partner counseling and referral services;
- AIDS Hotline referrals;
- Direct referrals from Ryan White programs' case managers; and
- Direct referrals for HIV-infected inmates discharged from the SC Department of Corrections.

South Carolina has developed an HIV/AIDS services infrastructure which provides a continuum of primary care, supportive services and other related services for persons with HIV disease who are uninsured or underinsured. Primary care services are provided either directly or by referral through the 11 Ryan White Title II care consortia, nine Title IIIb HIV Early Intervention Services, and Title IV pediatric care providers. The main medical care providers include private physicians, Title II funded clinicians, and primary health care/community health center physicians. Access to therapies is provided through the Title II AIDS Drug Assistance Program (ADAP), Medicaid, and pharmaceutical company drug assistance programs. Supportive services that enable persons to access and remain in primary care are provided directly by case managers in each Ryan White care program. Case managers link clients to substance use treatment, housing services, mental health counseling, food resources, and other supportive services.

Particular emphasis of all Ryan White Care providers is on increasing access to care and ensuring African American persons with HIV are linked to care services. Estimates of persons who are in care are based on several sources. Ryan White Title II consortia reported serving 7,194 persons during 2003; the AIDS Drug Assistance Program (ADAP) had 2,452 active clients in 2003. Clients served are essentially representative of the epidemic. In 2003, 76% percent of consortia clients were African American and 64% were male; 70% of ADAP clients were African American and 70% were male. The Ryan White Title IV program is a statewide, collaborative network of providers and organizations serving HIV exposed/infected infants, children, youth, women and their affected families, including male caregivers. Of the 650 clients served by Title IV programs in 2003, 543 or 84% were African American and 65% were youth under 12 and young adults 13-24 years.

The SC ADAP currently does not have a waiting list, due to Supplemental Funding awarded to needy states since the 2000 reauthorization of the Ryan White CARE Act. The number of clients continues to increase at a steady pace. Expenditures are also increasing, due to a larger number of patients being served and the increasing cost of new medications.

Minority AIDS Initiative (MAI) funding has allowed increased services to address racial disparities and ensure African Americans are linked to ADAP services and medical care in four

high prevalence areas of the state. The focus of these programs is to encourage a smooth and timely transition into care after diagnosis, and also to bring persons who have been lost to care back into care.

ADAP continues to manage an Insurance Assistance Program. Besides covering copayments and deductibles, the Insurance Program also pays for premiums for patients meeting eligibility requirements, thus allowing individuals to maintain insurance coverage. This program has been highly cost effective and extremely beneficial to clients. During 2003, the Insurance Assistance Program served 389 individuals.

In a recent community services assessment survey conducted statewide with 54 medical providers, 38 (70%) were urban and 16 (30%) were rural HIV care providers. Unmet needs for rural providers include use of Internet resources and education to increase comfort with and knowledge of Highly Active Antiretroviral Therapy (HAART) guidelines. Unmet needs for all providers include education about providing counseling for established patients regarding HIV transmission risk reduction, substance abuse management, and HIV status disclosure.

One of the cross-cutting issues identified by HIV care providers is that many people with HIV are non-adherent in taking medications as prescribed and with keeping appointments for medical care. This is rooted in many causes, such as fears of government programs, fear of family members and others learning their HIV status, side-effects of medications, lack of funds to pay for medications, depression, and low self-esteem. Ryan White providers are facing ongoing challenges associated with HIV treatment costs and problems with adherence to the often complex drug regimens. The Ryan White Statewide Coordinated Statement of Need (SCSN) addressed the issue of HIV drug adherence as one of the priority goals for the state. Solutions include implementing education and counseling interventions for clients as well as training providers on adherence issues and how to assist clients with psychosocial and environmental support systems to facilitate adherence.

Perinatal HIV Prevention Services

One of our greatest successes in HIV prevention is reducing mother to baby transmission. Routine screening of pregnant women and treatment for those infected continues to confine the proportion of infants born to HIV infected mothers who become infected to 2% each year from 14% in 1994. DHEC provides education and training opportunities to perinatal providers to ensure awareness of recommended screening and treatment guidelines. In 2004/2005, DHEC will participate in a CDC assessment of prenatal screening practices through medical chart review in eligible birthing hospitals to determine the proportion of pregnant women/infants receiving screening for HIV, syphilis, chlamydia, hepatitis B, Group B Streptococcus and rubella.

Services for infants born to HIV infected mothers are an essential component for perinatal HIV prevention. The South Carolina Ryan White Title IV program is a statewide, collaborative network of providers and organizations serving HIV exposed/infected infants, children, youth, women and their affected families, including male caregivers. DHEC's STD/HIV Division administers the program and oversees the performance of Title IV contractors and ten nurse case

managers in eight public health districts in the state. HIV specialty care is provided at three contracted, regional medical care facilities located across the state: Medical University of South Carolina (MUSC) in Charleston, University of South Carolina School of Medicine (USC) in Columbia, and the Greenville Hospital System (GHS). Each regional site has a case manager who works in conjunction with local public health nurse case managers (DHEC employees) to ensure that each family, including those living in very rural areas, receives appropriate follow-up, care coordination, and resource linkage based on medical and psychosocial needs. Expansion funding awarded in 2002 and 2003 established satellite specialty care clinics in rural areas challenged by the highest prevalence and incidence for HIV exposed/infected infants and distance to travel for specialty care: Florence (MUSC staffed), Sumter (USC staffed), and Spartanburg (GHS staffed).

In order to maintain these successes and to achieve elimination of perinatal HIV transmission in South Carolina, increased prevention strategies are needed that focus on women who receive inadequate or no prenatal care and on HIV-infected women with complex psychosocial issues who may not adhere to recommended antepartum or postpartum therapy and/or care plans. This will require increased provider training, increased coordination and linkages with existing systems of prenatal care providers and institutions, and specialized prevention case management services for HIV-infected pregnant women.

Preventing Homelessness: Housing Opportunities for People With AIDS (HOPWA)

Many persons with HIV face increased risks of homelessness due to the impact of the disease on physical health and the high cost of care and treatment. The average cost of medications alone per year is approximately $11,000. The Housing Opportunities for People With AIDS (HOPWA) grant from HUD provides funding to DHEC to help prevent homelessness. In addition, HUD directly funds the metropolitan statistical areas (MSAs) of Columbia, Charleston, Charlotte (includes York County), and Augusta (includes Aiken and Edgefield) to deliver HOPWA programs. Linkages to HOPWA services occur primarily through Ryan White case managers and local health department staff.

DHEC's HOPWA program continues to be a major portion of the delivery system of services to people and families living with HIV. Eleven contractors, experienced in providing a continuum of care for persons and families living with HIV/AIDS each year who are either homeless or at risk of becoming homeless, are recipients of HOPWA funds. Ten agencies provide short-term rent, mortgage and utility payments for persons with HIV/AIDS and their families. Project Care, a community residence in Greenville, continues to be funded through state HOPWA funding. Contractors also use HOPWA funds to provide case management and supportive services, and all are closely linked with Ryan White care providers. This assures a coordinated system of delivery to eligible persons and families with HIV/AIDS.

During FY 2004, DHEC's HOPWA funds for areas not covered by the direct-funded MSAs are expected to provide approximately 1500 eligible persons with Short Term Rent, Mortgage, and Utilities (STRMU) assistance and supportive services, and more than 300 eligible persons will receive supportive services not associated with housing assistance. It is estimated that 75

persons will receive tenant-based rental assistance. Identification of additional resources to use in leveraging HOPWA funding will be actively sought out.

Three long-term housing projects were funded in recent years: two tenant-based rental assistance projects, one in Fort Mill and the second in six rural counties surrounding Florence, and new construction of twelve units in Greenville. During FY 2003, an ongoing statewide tenant-based rental assistance program was developed. This focus on long-term housing is a response to the changing HIV epidemic and assessment/prioritization of permanent housing in South Carolina. In late 2004, an RFP will be issued for additional innovative long term housing to fill further housing needs of persons living with HIV in South Carolina.

Ongoing needs assessments with care and support service providers and with persons living with HIV indicate that, while there is variance around the state, there is a high demand for adequate, affordable housing. There are long waiting lists for subsidized housing, a lack of low-income, safe, and quality housing for low-income individuals, particularly single men with a history of substance abuse and incarceration. Specific types of housing needed include stable low-income housing, temporary shelters, advanced care facilities for those requiring medical assistance, and a hospice facility. None of the available shelters are prepared to provide quality assisted living for persons with HIV.

Substance Use Treatment and Mental Health Services

Substance use treatment is primarily provided by the county alcohol and drug abuse facilities upon referral by counseling and testing staff and Ryan White care providers. Mental health services are provided through the local mental health centers and with a few consortia that have staff to provide psychosocial assessments and counseling. These two services remain two of the most often identified unmet needs, particularly in rural areas of the state. Access to substance use treatment or mental health services is often limited by a lack of treatment slots and inability to pay for services. State and local agencies have received significant state budget reductions in the past three years, resulting in reduced number of staff, facilities and services throughout the state.

Corrections Systems

The state correctional facilities (SC Department of Corrections; SCDC) currently house all HIV-infected inmates in two facilities, one for men and one for women. This enables the SCDC to better coordinate care and support services to infected inmates. All new inmates receive mandatory HIV screening and if positive are placed in the designated facility. Recently, SCDC has an average of 500 men and 37 woman inmates who are HIV-infected. During the past four years, SCDC staff, state Ryan White Title II and Midlands Care Consortium staff have met to plan and develop a system of discharge to ensure inmates living with HIV are efficiently linked to the consortia and care services within thirty (30) days of release. This is to ensure a continuity of care and maintenance of therapies currently taken while in correctional facilities.

HIV/STD screening services are more limited for county/city jail inmates. This is primarily due to lack of financial and/or staff resources and, in some cases, a short incarceration time that

prohibits inmates who might be tested in a facility from getting results prior to discharge. HIV and syphilis testing is conducted in several county jails in conjunction with syphilis elimination efforts. Partner counseling and referral staff assist in providing test results counseling and referrals to care providers upon release.

Needs assessments have been conducted with both state- and county-released HIV-infected inmates to determine their most immediate health and social services needs. Results are shared with prevention and care providers to assist in development of improved discharge planning systems.

Key Recommendations for Enhancing Coordination and Linkages

Provide and support ongoing opportunities for state and local HIV prevention providers to coordinate services through joint trainings, needs assessment activities, sponsorship of events, resource-sharing, development of evaluation plans, and continued collaboration.

Increase awareness of existing services and programs by other state and local agencies. Develop and enhance collaborative marketing strategies between such agencies and organizations as SC DHEC, the SC HIV/AIDS Council, AIDS service organizations, TEAM, the SC Primary Health Care Association, and others.

Recruit participation and/or membership from diverse agencies, non-governmental and community-based organizations, institutions, providers, and consumers for the SC HIV Planning Council, including mental health and substance use treatment services agencies.

Provide training and technical assistance to prevention and care providers to ensure they have culturally competent, client-centered skills to assess the range of health and social needs of clients in order to make appropriate referrals.

Continue to provide training and technical assistance to prevention and care staff on client-centered counseling skills and how to make active referrals.

Obtain input and ideas from the Consumer Advisory Committee of the SC HIV/AIDS Council on best approaches to increase awareness of target populations' knowledge of prevention and care services and the skills necessary to access and navigate the "system."

Coordination efforts should continue among prevention providers, as well as between prevention and care providers, to identify and resolve barriers to linkages to related services, integrating training and needs assessment efforts as appropriate to avoid duplication, and to maximize existing resources.

Providers should explore options to enhance linkages from prevention to care services by using peers or near-peers as "bridges" to services, incentives, and seamless systems of prevention and care.